SUPPORTING CHILDREN WITH COMPLEX COMMUNICATION NEEDS TO COMMUNICATE CHOICES DURING AN INPATIENT STAY: EFFECTS OF AN AAC PARTNER TRAINING

Jessica Gormley, M.A., CCC-SLP

Pennsylvania State University

OBJECTIVES

1. Share results of a study that evaluated the impact of a AAC partner training to teach healthcare providers to support child communication of choices during inpatient interactions
2. Discuss, as a group, strategies to conduct rigorous intervention research in health care settings

ACKNOWLEDGEMENTS

- A grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant #90RE5017) to the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication (The RERC on AAC)
- The Penn State AAC Doctoral Leadership grant from the U.S. Department of Education (grant #H325D170024)
- 2018 New Century Scholars Doctoral Scholarship granted by the American Speech-Language Hearing Foundation (ASHFoundation)
- 2018-2019 Kligman Graduate Fellowship from the College of Health and Human Development at Pennsylvania State University
- The families and healthcare providers who participated in this research

"Communication is the most common 'procedure' in medicine."

(Levetown & the Committee on Bioethics, 2008, p. e1441)

THE PROBLEM

- A severe communication disability can negatively impact the quality of life, health outcomes, and participation of individuals with complex communication needs in medical encounters (Beukelman, Blackstone, & Yorkston, 2015)
- Adults with complex communication needs experience 3 times more preventable adverse medical events (Bartlett, 2008)
- Reducing communication barriers of individuals with CCN in acute care facilities could prevent over 600,000 adverse events annually (projected savings of $6.8 billion) (Hurtig, Alper, & Berkowitz, 2018)
- Children with complex communication and medical needs often experience frequent and/or extensive hospitalizations (Burns et al., 2010)

CHILDREN WITH COMPLEX COMMUNICATION NEEDS IN THE HOSPITAL:

- Rely on augmentative and alternative communication (AAC) strategies to communicate
- Experience multiple challenges communicating with staff (Shilling et al., 2012)
- Often play passive roles during interactions (Hemsley et al., 2013)
- Have expressed a desire to more actively participate in interactions (Hemsley et al., 2013)

IN INPATIENT ENVIRONMENTS

Children with CCN may:

- Have restricted communication with adults
- Have limited access to toys
- Interact with a large number of unfamiliar partners
- Have limited linguistic input in a mode they can easily produce
- Have existing or newly acquired neurological conditions that make communication and language learning challenging

(Gormley & Light, 2019b & c)

HOSPITAL PROVIDERS WHO SERVE CHILDREN WITH DISABILITIES REPORT:

- Time constraints as a critical barrier to effective communication (e.g., Hemsley & Balandin, 2014)
- Limited training to effectively communicate with individuals with complex communication needs (e.g., Finke et al., 2008)
- Supporting the child's communication in hospitals is not part of their roles on the interdisciplinary team (Sharkey et al., 2016)
- Prioritizing other aspects of care (e.g., feeding) above communication (Hemsley et al., 2014)

IMPLICATIONS FOR TRAINING

- Consider efficient and effective methods to train a large number of communication partners, across a variety of settings and locations, for potentially short durations of time.
- Provide consistent opportunities for the child to actively control aspects of the interaction
- Train health care providers and parents to be responsive to child communication attempts with diverse linguistic input

WHY TEACH CHOICE-MAKING?

- Promotes child control and active participation in medical encounters (Palazzi et al., 2015)
- Early developing skill exhibited by children in the intentional and early symbolic levels of communication (Siegel & Cress, 2002)
- Can be used:
  - with children who use a variety of AAC techniques (e.g., eye gaze)
  - across a variety of contexts and activities
- It is quick to learn and easy to implement

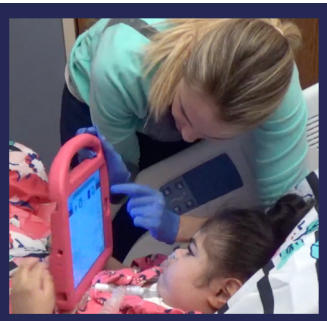
RESEARCH QUESTIONS

(a) What is the effect of the training on the percentage of rehabilitation providers who offer a child with CCN a choice during routine interactions?

(b) What is the effect of the training on rehabilitation providers' accuracy implementing the steps of the choice-making strategy with children with CCN during routine interactions?

(c) What is the perceived value of the training based on rehabilitation providers' self-report?

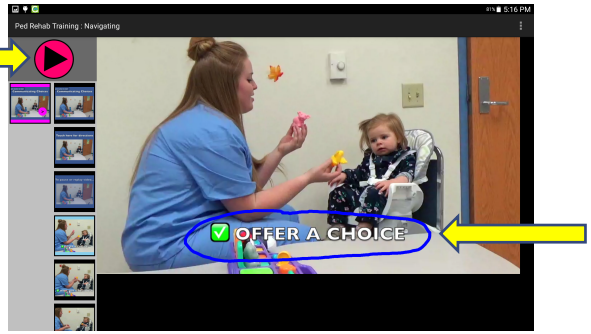
(d) What is the effect of the training on the children's communication of choices during routine interactions?



JUST-IN-TIME TRAINING FORMAT

(Branzetti et al. 2017; Mangum et al., 2017)

Brief	• 15-minutes in duration
Portable	• Housed on a tablet
Task-Driven	• Focused on procedural learning of a single, well-defined task (i.e., choice-making)
Multimedia Elements	• Video cases, audio narration, and text used to explain and demonstrate content
User-Driven & Instructor-Driven	• Instructor pre-programmed pause points & explanation • User controlled the rate of completion and navigation



"COMMUNICATING CHOICES" MOBILE TRAINING

COMMUNICATING CHOICES

OFFER A CHOICE
- ☐ Pick 2 objects
- ☐ Ask a question
- ☐ Show and name

WAIT FOR A RESPONSE
- ☐ Watch the child
- ☐ Remain silent

RESPOND TO THE CHILD

If the child...	Say		Do
Picks an item	"You want ___"	+	give the item to the child
Rejects the items	"You don't want ___"	+	present different items
Does not respond	"I don't know what you want"	+	repeat the same items

"COMMUNICATING CHOICES" CHECKLIST

ADULT PARTICIPANTS (N = 28)

- Nurse (n = 6)
- Certified Nursing Assistant (n = 4)
- Respiratory Therapist (n = 6)
- Speech-Language Pathologist (n = 3)
- Occupational Therapist (n = 4)
- Physical Therapists (n = 3)
- Recreational Therapists (n = 2)

Jacinta
- 17 months old
- Septic shock syndrome resulting in multiple amputations

Gerome
- 16 years old
- Anoxic brain injury, previously typically developing

Adriana
- 16 years old
- Rare chromosomal disorder, in ICU for 1 year prior to admission to rehab facility

CHILDREN WITH COMPLEX COMMUNICATION NEEDS (N = 3)

STUDY PROCEDURES

Group	Time 1		Time 2
Treatment (n = 14)	2 Child Interactions (Pretest)	Training + Checklist Social Validity Questionnaire	2 Child Interactions (Posttest)
Control (n = 14)	2 Child Interactions (Pretest)		2 Child Interactions (Posttest)

DEPENDENT VARIABLES

Variable	Description
Percentage of rehabilitation providers who offered a choice	The total number of providers in each group that offered at least one choice/(the total number of providers in the group) X 100
Accuracy of procedure implementation	The total number of procedure steps accurately implemented by the provider during child interaction 1 + child interaction 2
Percentage of interactions when children communicated a choice	The total number of interactions that a child accepted or rejected a choice in each time point/(total number of interactions in each time point) X 100

DATA CODING

- Prior to coding, two research assistants completed a training of the operational definitions
- Child-provider interactions were coded using the operational definitions of each dependent variable by a research assistant blind to group assignment and pre-post condition.
- A second research assistant, also blind to group assignment and condition, coded 25% of the child interaction videos to achieve interobserver reliability.

DATA ANALYSIS

- Descriptive statistics were completed to calculate:
  - The percentage of healthcare providers who offered a choice across each group and time point
  - The accuracy of procedure implementation by providers across each group and time point
  - The percentage of interactions when the children (a) selected an item, (b) rejected both items, or (c) did not respond to the provider when offered a choice
- The Kruskal-Wallis test was used to investigate the effects of the training on the accuracy of procedure implementation between groups
- Eta-squared was calculated to measure the clinical significance of these effects

RESULTS – HEALTHCARE PROVIDERS WHO OFFERED A CHOICE

Group	Pretest Interactions	Posttest Interactions
Treatment (n = 14)	0% (n = 0)	71% (n = 10)
Control (n = 14)	14% (n = 2)	7% (n = 1)

ACCURACY OF PROCEDURE IMPLEMENTATION

Pretest Performance

Group	Mean Pretest Score	Median Score	U	P	η^2
Treatment	0 (0)	0	84.00	0.15	0.07
Control	2.0 (5.6)	0			

Gain Scores (Posttest – Pretest)

Group	Mean Gain Score (SD)	H(1)	P	η^2
Treatment	+11.6 (8.9)	12.597	0.001**	0.44
Control	-1.4 (6.3)			

SAMPLE PRE-TEST INTERACTION

SAMPLE POST-TEST INTERACTION

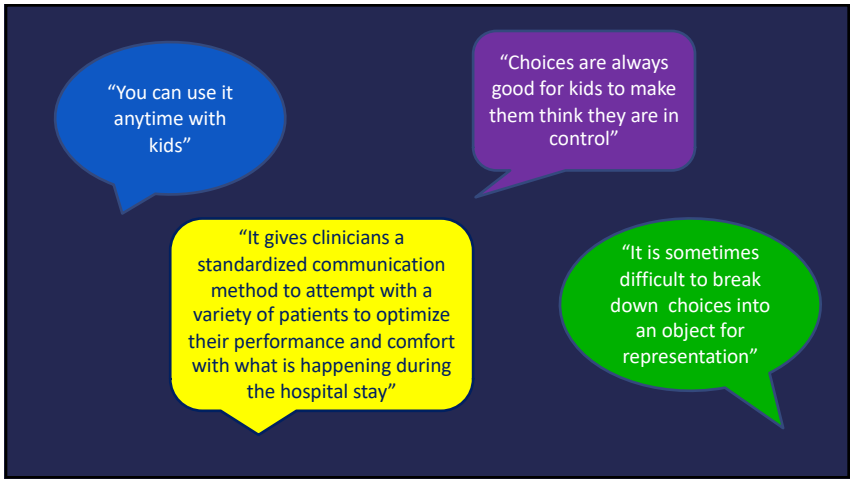
CHILD PARTICIPATION DURING INTERACTIONS (TREATMENT GROUP)

Pretest:

- **Providers did not offer children a choice in any pretest interaction**
- **Children communicated a choice during 0% (n = 0) of interactions**

Posttest:

- **Providers offered children a choice in 16 posttest interactions**
- **Children communicated a choice during 94% (n = 15) of interactions when a choice was offered**



LIMITATIONS

- Although improvements were observed in the treatment group, a small number of providers still did not offer a choice following the training → may need additional training and/or a different training mode
- Due to time constraints on the unit, maintenance of the target skill was unable to be measured
- The training only addressed one interaction skill

DISCUSSION

- Following training completion (total of 15 minutes):
  - more healthcare providers offered a choice to a child with CCN after completing the training
  - inpatient providers completed the "Communicating Choices" procedure with increased accuracy
  - children with complex communication needs consistently communicated their choices, when given the opportunity to do so
- The training may be an effective intervention approach to support children with CCN to communicate their preferences in the inpatient setting

UNDERSTANDING AND IMPROVING AAC SERVICES IN INPATIENT SETTINGS

Project 1: Online Focus Groups of Inpatient Rehab SLPs → Project 2: Descriptive Studies of Child-(Parent)-Provider Interactions → Project 3: AAC Communication Partner Training for Pediatric Rehab Staff → Future Projects: AAC Communication Partner Training for In-service and Pre-service Healthcare Staff

DISCUSSION TOPIC

- How can we design research studies that rigorously evaluate the impact of AAC trainings within healthcare settings, given its unpredictable and dynamic nature inpatient settings?
  - Recruitment and retainment of participants
  - Challenges maintaining experimental control (e.g., unexpected discharges, admissions, staff work assignments)
  - Real-world evaluation of short-term and long-term effects of the treatment

REFERENCES

- Bartlett, G., Blais, R., Tamblyn, R., Clermont, R.J., & MacGibbon, B. (2008) Impact of patient communication problems on the risk of preventable adverse events in acute care settings. *Canadian Medical Association Journal, 179,* 1555-1562. Doi: 10.1503/cmaj.070690
- Blackstone, S.W., Beukelman, D.R., & Yorkston, K.M. (eds.). (2015). *Patient-provider ommunication: Roles for speech-language pathologists and other health care professionals*. San Diego, CA: Plural Publishing Inc.
- Branzetti, J.B., Adedipe, A.A., Gittinger, M.J., Rosenman, E.D., Brolliar, S., Chipman, A.K... & Fernandez, R. (2017). Randomised controlled trial to assess the effect of a just-in-time training on procedural performance: A proof-of-concept study to address procedural skill decay. *BMJ Quality & Safety, 26,* 881-891. Doi: 10.1136/bmjqs-2017-006656
- Burns, K.H., Casey, P.H., Lyle, R.E., MacBird, T., Fussell, J.J., & Robbins, J.M. (2010). Increasing prevalence of medically complex children in US hospitals. *Pediatrics, 126,* 638-646. Doi: 10.1542/peds.2009-1658

REFERENCES

- Finke, E.H., Light, J., & Kitko, L. (2008). A systematic review of the effectiveness of nurse communication with patients with complex communication needs with a focus on the use of augmentative and alternative communication. *Journal of Clinical Nursing*, *12*, 2102-2115.
- Gormley, J., & Light, J. (in press). Providing services to individuals with complex communication needs in the inpatient rehabilitation setting: The experiences and perspectives of speech-language pathologists. *American Journal of Speech-Language Pathology.*
- Gormley, J., & Light, J. (2019b). Hospitals as a language learning context for children with complex medical needs. Manuscript in preparation.
- Gormley, J., Light, J. (2019c). Patient-parent-provider interactions of a young child with complex communication needs in a pediatric rehabilitation facility. Manuscript in preparation.
- Hemsley, B., & Balandin, S. (2014). A metasynthesis of patient-provider communication in hospital for patients with severe communication disabilities: informing new translational research. *Augmentative and Alternative Communication*, *30*, 329–343.
- Hemsley, B., Kuek, M., Bastock, K., Scarinci, N., & Davidson, B. (2013). Parents and children with cerebral palsy discuss communication needs in hospital. *Developmental Rehabilitation*, *16*, 363-374. doi:10.3109/17518423.2012.758187
- Hemsley, B., Lee, S., Munro, K., Seeda, N., Bastock, K., & Davidson, B. (2014). Supporting communication for children with cerebral palsy in hospital: Views of community and hospital staff. *Developmental Neurorehabilitation*, *17*, 156-166.

REFERENCES

- Hurtig, R.R., Alper, R.M., & Berkowitz, B. (2018). The cost of not addressing the communication barriers faced by hospitalized patients. *Perspectives of the ASHA Special Interest Groups SIG 12, 3,* 99-112. Doi: 10.1044/persp3.SIG12.99
- Levetown, M., & and the Committee on Bioethics. (2008). Communicating with children and families: From everyday interactions to skill in conveying distressing information. *Pediatrics*, *121*, e1441–e1460.
- Mangum, R., Lazar, J., Rose, M.J., Mahan, J.D., & Reed, S. (2017). Exploring the value of just-in-time teaching as a supplemental tool to traditional resident education on a busy inpatient pediatrics rotation. *Academic Pediatrics, 17,* 589-592.
- Sharkey, S., Lloyd, C., Tomlinson, R., Thomas, E., Martin, A., Logan, S., & Morris, C. (2016). Communicating with disabled children when inpatients: barriers and facilitators identified by parents and professionals in a qualitative study. *Health Expectations*, *19*, 738–750.
- Siegel, E.B., & Cress, C.J. (2002). Overview of the emergence of early AAC behaviors: Progression from communicative to symbolic skills. In J.R. Reichle, D.R. Beukelman, & J.C. Light (Eds.), *Exemplary practices for beginning communicators*. (pp. 25-58). Baltimore, MD: Brookes.